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**RURAL LOW BIRTH WEIGHT CHILDREN AND THEIR FAMILIES:
VISIONS FOR THE FUTURE**

Final Report - Grant # R13 HS07950-01A1

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Barbara Sachs, PhD, RN, Principal Investigator

and

Lynne A. Hall, DrPH, RN, Co-Principal Investigator

College of Nursing

University of Kentucky

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13. ABSTRACT (Maximum 200 words) The conference aims were to: 1) improve communication, networking and collaboration between tertiary care and community based providers of health care to rural low birthweight (LBW) children and their families; 2) develop recommendations for changes in health care practice and health care policy and programs, as well as to suggest new research directions for LBW children and their families in rural settings; and 3) disseminate recommendations based on conference proceedings to health care providers, policymakers, and researchers. Program content was based on responses to two preconference Delphi surveys about barriers to care for these families. Barriers to care included family, provider, and systems issues. Conference participants included parents, health care professionals, and policymakers. Conference format included both large and small group sessions. Strategies suggested to overcome barriers were related to transportation, finances, improved provider-family communication, and better care coordination.			
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I. IDENTIFYING INFORMATION

- A. Principal Investigator: Barbara Sachs, PhD, RN, FAAN
Professor
University of Kentucky
529 College of Nursing
Lexington, KY 40536-0232
- B. Grantee institution - University of Kentucky
- C. Grant number - R13 HS07950-01A1
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II. EXECUTIVE SUMMARY

Reducing the incidence of low birth weight and subsequent morbidity and mortality in children is an objective of Healthy People 2000 (US Public Health Service, 1990).

Approximately 250,000 low birth weight (LBW) children are born annually in the United States (Institute of Medicine, 1985), comprising about 7% of all births (Institute of Medicine, 1985). In Kentucky, approximately 7% of children weigh less than 2,500 grams at birth; 23% are born to adolescent mothers (Kentucky Cabinet for Human Resources, 1990). Nearly 18% of the LBW children are born to unmarried mothers, and 45% of these mothers have less than a high school education. These data indicate a need for effective health services.

Needs of LBW families. Effective parenting can offset limitations of biomedically at risk infants (Sameroff & Chandler, 1975; Nurcombe et al., 1984). However, the birth of a premature child is an emotional crisis for the parents (Kaplan, 1968; Kaplan, & Mason, 1960), taxing their ability to effectively parent the child with special needs. The care required by the child may be difficult for the parent to provide and may be complex enough that it prevents the family from meeting other responsibilities without instrumental support. Community resources to support families of LBW children may be less available and/or accessible in rural communities than in urban settings.

Characteristics of the LBW child add to the parents' difficulty. The appearance may be aversive (Rauh, Nurcombe, Achenbach, & Howell, 1990). The unusual physical characteristics of these infants increase perceptions of their vulnerability (Ramey, Bryant, Sparling, & Wasik, 1984). Compared to normal birth weight children, LBW children have more medical

complications (McCormick, 1985), developmental delays (Shapiro, McCormick, Starfield, Kricher, & Bross, 1980), behavioral maladjustment (Escalona, 1982), and cognitive deficits (Escalona, 1982), as well as lower academic competence (Scott, 1987).

Barriers to Care. The health resources available in Eastern Kentucky are provided through health departments, mental health agencies, or the social services department. This is a particular problem for Kentucky because 65% of the state's 3.5 million residents live in rural areas (Economic Development Council, Commonwealth of Kentucky, 1990) which have been classified by the National Health Services as underserved. Thus, the likelihood that the overextended providers understand the specific needs of families with LBW children, or can address those unique needs, is limited.

Although some services are available, coordination of existing services is a major need (Middendorf, 1991). Accessibility of services for this mountainous area is another issue. Other recognized barriers to quality health care resources are lack of provider knowledge about what is available, difficulty in maintaining current knowledge about agencies, policies, procedures, and funding, and lack of cooperation and collaboration between agencies (Middendorf, 1991).

Intervention Studies. Although interventions to improve health outcomes have been implemented with children at both psychosocial and biological risk, few studies have been conducted with rural populations. Studies to decrease parental stress and enhance child-rearing skills have had mixed results. Paraprofessionals had difficulty implementing a set curriculum because of multiple chronic stressors facing the low-income mothers of healthy neonates (Siegel et al., 1980). However, in a study of high-risk, semi-rural families where adequate medical

services were available, Olds and colleagues (1986, 1988, 1989, 1990) enhanced educational achievement, promoted employment, and reduced repeat pregnancies among young mothers with healthy infants using home visits by nonbaccalaureate prepared nurses. The visits began prenatally and extended for two years. Interventions included parent education, developing informal support systems with the parent, and linking the parent to the formal support system.

The studies related to biological risk of neonates may be difficult to extrapolate to Eastern Kentucky, because they were conducted in urban settings (Broton et al., 1986; Hunter, Kilstrom, Kraybill, & Loda, 1978). Other investigators used a comprehensive intervention approach that was judged effective, but information was not provided about the effects of attention versus intervention, the qualifications of the home interventionist, or responses of rural families included in the sample. Generally the studies provided support for interventions improving either parent skills, child development, or both (Achenbach, Phares, Howell, Rauh, & Nurcombe, 1990; Nurcombe et al., 1984; Resnick, Eyler, Nelson, Eitzman, & Bucciarelli, 1987; Rauh et al., 1990).

Setting and Participants. The conference was held in rural Kentucky at the Carriage House Hotel, Paintsville, Kentucky. This facility was selected to facilitate travel for the 65 attendees. Participants were identified by the Advisory Board and the investigators to represent both geographically diverse areas of rural Eastern Kentucky, as well as tertiary care centers, and a broad scope of providers of health care to LBW children and their families, policy makers, and parents. Participants included physicians, nurses, home health providers, mental health providers, a social worker, physical and occupational therapists, and parents.

In addition to recommending participants for the conference, the Advisory Board's other functions were to: (a) advise on conference aims, content, learning activities, schedule, and speakers; (b) participate in both rounds of the Delphi survey to identify and refine child and family needs; (c) moderate sessions at the conference, and (d) contribute to preparation of policy recommendations and the final report.

Assessment of learner needs. Conference participants were identified early so that they could participate in a two-round Delphi survey technique designed to refine conference content and materials to be shared at the meeting. The first Delphi survey determined the provider-identified needs of families with LBW children. The second Delphi survey reduced the list of identified needs to a number which could be addressed in the conference work group sessions.

Methodology

The long-term goal of a conference for parents, providers, and health policy makers was to improve the health outcomes of low birth weight (LBW) children and their families residing in a portion of rural Eastern Kentucky. Specific Aims were to: (a) enhance communication, networking, and collaboration between tertiary care and community-based providers of health care to rural LBW children and their families; (b) identify community resources available, commonly used, not used, or not available to rural LBW children and their families; (c) identify common unmet health needs of these children and their families from the perspective of health care providers; (d) facilitate sharing of current clinical research findings on community-based care of low birth weight infants; (e) analyze ways to improve access to and delivery of high quality health care for these children and families; and (f) develop and disseminate

recommendations to health care providers and funding agencies based on conference proceedings.

The conference, a two-day meeting of parents, policy makers, and providers of care to rural LBW children and their families used a multi-phase effort to accomplish the Specific Aims. Phase 1 included detailed planning for the conference with an Advisory Board. Phase 2 was the conference implementation effort, while the last three phases were data analysis, evaluation of conference influence on practice, and development and implementation of a program under the auspices of a county health department to provide support to parents of LBW children.

Registration packets were prepared to include conference aims, abstracts of recent LBW research, conference sponsors, brochures about early intervention and support services, the Delphi survey summaries, and the conference agenda.

Conference Methods

The conference methods included small group and total group sessions. Drs. Virginia Rauh and Patrick Casey shared their research on models for enhancing health care to LBW children and their families, while Dr. Rice Leach addressed Kentucky health care reform related to families with children. Parents also spoke about what it meant to them to care for a LBW child at home over time.

Participants were assigned to small groups to facilitate interdisciplinary discussions. The groups were asked to: (a) evaluate existing research for potential application to the identified needs of LBW families; (b) suggest strategies to improve health care; (c) recommend policy or program changes to improve health outcomes for these children and families; and (d) identify

topics for rural research on LBW children and families. On Day 1, they focused primarily on barriers and strategies. Moderators met at the end of Day 1 to revise plans for Day 2, to address research applications and to propose models for improving care.

Problems Encountered

The major problem encountered was the lack of attention in the small groups to the applications of existing research and to policy recommendations. The policy recommendations made by the small groups all required additional funding sources, while some ideas were not feasible. For example, suggestions for changes in requirements for disability and medical coverage.

Outcomes

The keynote speakers emphasized communication, community involvement, and political activity. According to participants the highlight of the conference was the discussion led by parents about their concerns and the adaptations required of them from the time of their LBW child's discharge from the hospital until the present. They spoke of co-workers and family members who supported them, transportation needs, and financial burdens, illustrating each point with poignant stories.

Barriers. A total of 51 barriers were identified by the small groups. Family barriers included denial of a problem, lack of parenting skills, lack of support, transportation issues, and financial concerns. Provider issues cited were lack of family-centered care, lack of knowledge of resources, not speaking in terms parents could understand, and not taking enough time with families. Some of the system issues included financial/funding issues, lack of coordinated

services, transportation issues, poor inter-provider communications, and lack of prevention emphasis in health care.

Strategies. The brainstorming sessions developed 53 strategies to enhance care. Many of the proposed strategies were related to better communication, support services for parents, and transportation suggestions. Strategies suggested included designated liaisons between service programs, widely disseminated and frequently updated resource manuals, more referrals to meet needs, efforts to develop coping skills in families and provides, preventive interventions, parent education programs, improved curricula for health providers, respite care, satellite clinics, and specialized day care.

These issues were collapsed into six general categories: (a) coordination of services at the family level; (b) coordination of services at the system level; (c) financial resources; (d) parent and public health promotion/illness prevention education; (e) transportation; and (f) provider issues (practice, accessibility, education, and the mix of rural provides). The participants strongly emphasized the need for consumers to be involved, in addition to developing community-based models.

Specific strategies for overcoming barriers included: training and re-training for rural providers; medical cards if the children were ineligible; and greater use of computer technology to share databases. School-based family health and resource centers were recognized as valuable and the need to expand them into more areas was acknowledged. There was a strong plea to have one coordinator of services for each family, although no strategies were suggested for accomplishing this goal. The amount of agreement on barriers to care and strategies for

overcoming the barriers was encouraging because with so much similarity between different rural areas, changes in service delivery to address these issues should generalize across counties and regions.

A nursing consultant from the Maternal-Child Health Bureau Atlanta office summarized the accomplishments of the conference, echoing the themes developed in the groups which emphasized prevention. She suggested that services be simple and individualized rather than focusing on program guidelines. She pleaded for combining resources to deliver services, eliminating duplication, and enhancing care. Joint funding for transportation with other community agencies was another point, as well as local, community-based planning with evaluation of child, family, and system being a critical issue. The final point was that consumers needed input into policy changes.

Post Conference Activities

Following the conference, the investigators met with state and local leaders who were interested in pursuing change. A proposal, developed by the PI and Co-PI, was discussed with one rural county health department and was sent to the state for funding approval. A program, LBW Family Support Services, was developed and is being pilot tested in one county. Evaluation of program effectiveness will be conducted by the investigators. Program implementation began with the recruitment and training of personnel. The investigators were assisted in the training efforts by skilled personnel (RN and MD) from a level II neonatal nursery at the Pikeville Methodist Hospital. Partial support for the effort was provided by private funding. Dissemination of recommendations to policy makers and researchers is awaiting

evaluation of the pilot program outcomes. If successful, efforts will be initiated to expand the program to other areas.

III. ABSTRACT

The conference aims were to: (1) improve communication, networking, and collaboration between tertiary care and community-based providers of health care to rural low birth weight (LBW) children and their families; (2) develop recommendations for changes in health care practice and health care policy and programs as well as to suggest new research directions for LBW children and their families in rural settings; and (3) disseminate recommendations based on conference proceedings to health care providers, policy makers, and researchers.

Program content was based on responses to two pre-conference Delphi surveys about barriers to care for these families. Sixty-five parents, health care professionals, and policy makers representing diverse disciplines and rural areas attended. Four speakers and a parent panel were interspersed with small and large group sessions to meet conference aims.

Barriers to care included family, provider, and systems issues. Strategies suggested to overcome barriers were related to transportation, finances, improved provider-family communication, and better care coordination. A program of family support services for LBW children and families to improve communication and coordination, a project that resulted from the conference, is being pilot tested in one rural Kentucky county.

IV. PROJECT STAFF

Barbara Sachs, PhD, RN, FAAN (PI), Professor of Nursing; 9/30-94 - 9/29/96

Lynne A. Hall, DrPH, RN (Co-PI), Associate Professor of Nursing and Behavioral
Science; 9/30/94 - 9/29/96

Anja Peersen, MSN, RN (Research assistant); 1/15/95 - 8/1/95

Libby Moss, Secretary; 9/30/94 - 9/29/96

Dorothy Redfern, MSPH, RN (Consultant), Region IV, Maternal Child Health Bureau,
Department of Health and Human Services, Atlanta, GA

Virginia Rauh, SCD, Associate Professor, School of Public Health, Columbia University,
New York

Patrick Casey, MD, the Harvey & Bernice Jones Professor of Developmental Pediatrics
& Psychiatry, University of Arkansas Medical Science Campus, Little Rock, Arkansas

V. PURPOSE OF THE STUDY

A. Overall Objective

The long-term goal of this conference was to improve health outcomes of low birth
weight (LBW) children and their families residing in rural Eastern Kentucky.

B. Specific Aims

The Specific Aims were to:

- Enhance communication, networking, and collaboration between tertiary care and
community-based providers of health care to rural LBW children and their
families.

- Identify community resources available, commonly used, not used, and not available to rural LBW children and their families.
- Identify common unmet health needs of these children and their families from the perspective of health care providers.
- Facilitate sharing of current clinical research findings on community-based care of LBW children.
- Analyze ways to improve access to and delivery of high quality health care for these children and families.
- Develop and disseminate recommendations to health care providers and funding agencies based on conference proceedings.

VI. BACKGROUND TO THE STUDY

A. Statement of the Problem

Reducing the incidence of low birth weight and subsequent morbidity and mortality in children is an objective of Healthy People 2000 (US Public Health Service, 1990). There are approximately 250,000 LBW children born annually in the United States; LBW children comprise approximately 7% of all births each year (Institute of Medicine, 1985). In Kentucky, approximately 7% of children weigh less than 2,500 grams at birth; of these 23% are born to adolescent mothers (Kentucky Cabinet for Human Resources, 1990). Nearly 18% of the LBW children are born to unmarried mothers, and 45% of the mothers have less than a high school education (Kentucky Cabinet for Human Resources, 1990). In a study of Eastern Kentucky high-risk infants, including LBW infants, approximately 15% of them died within one year of

birth for unclear reasons (Personal communication, D. Fisher, January 3, 1991). This indicated the need for improved health care services for these children and their families.

B. Review of the Literature

Needs of LBW families. Research on biomedically at risk infants has demonstrated that effective parenting can offset environmental limitations (Sameroff & Chandler, 1975; Nurcombe, Howell, Rauh, Teti, Ruoff, & Brennan, 1984). However, the birth of a premature child is an emotional crisis for the parents (Kaplan, 1968; Kaplan & Mason, 1960), taxing their ability to effectively parent the child with special needs. The mother may feel inadequate as a woman because she was unable to carry the fetus to term. The care required by the child may be difficult for the parent to provide. This adds to frustration and feelings of incompetence and places the family at risk for poor coping (Failla & Jones, 1991). The care of the LBW child may be complex enough that it prevents the family from meeting other responsibilities without instrumental support. Community resources to support families of LBW children exist in urban settings, but they are less available and/or accessible in rural communities.

Characteristics of the LBW child add to the parents' difficulty. The appearance may be aversive (Rauh, Nurcombe, Achenbach, & Howell, 1990). The unusual physical characteristics of these infants increase perceptions of their vulnerability (Ramey, Bryant, Sparling, & Wasik, 1984). They experience few organized quiet alert states, and there is little reserve energy for social interaction with the parent (Rauh et al., 1990). Compared to normal birth weight children, LBW children have more medical complications (McCormick, 1985), developmental delays (Shapiro, McCormick, Starfield, Krischer, & Bross, 1980), behavioral maladjustment (Escalona,

1982), and cognitive deficits (Escalona, 1982), as well as lower academic competence (Scott, 1987).

The child's characteristics and the parents' feelings and attitudes provide a less than optimal situation for parenting the at-risk LBW child. Both the family's adjustment to parenthood and the child's development may be compromised (Sameroff & Chandler, 1975).

Barriers to Care. The health resources available in Eastern Kentucky are provided through health departments, mental health agencies, and the social services department. Because 65% of Kentucky's 3.5 million residents live in rural areas (Economic Development Council, Commonwealth of Kentucky, 1990) classified by the National Health Services as underserved, the likelihood that the overextended providers understand the specific needs of families with LBW children, or can address those unique needs, is limited.

Although services are available to families with LBW children, coordination of existing services is a major need (Middendorf, 1991). Accessibility of services for this mountainous area is another issue. Other recognized barriers to quality health care resources include lack of provider knowledge about available resources, difficulty in maintaining current knowledge about agencies, policies, procedures, and funding, and lack of cooperation and collaborative endeavors among agencies (Middendorf, 1991).

Intervention Studies Although interventions to improve health outcomes have been implemented with children at both psychosocial and biological risk (Brooten et al., 1986; Hack et al., 1993; Orr, James, & Casper, 1992), few studies have been conducted with rural populations (Bradley et al., 1993; Olds, Henderson, Tatelbaum, & Chamberlin, 1986). Interventions have

been implemented with urban (Brooten et al., 1986) and semi-rural (Olds, Henderson, Tatelbaum, & Chamberlin, 1986), healthy and high-risk neonates with services provided by para-professionals and nurses (Olds & Kitzman, 1990) with varying educational preparations. Interventions have been tested prenatally (Hunter, Kilstrom, Kraybill, & Loda, 1978) and at several points in time postnatally, continuing up to three years.

Interventions to decrease parental stress and enhance child-rearing skills have had mixed results. Paraprofessionals had difficulty implementing a set curriculum because of multiple chronic stressors facing the low-income mothers of healthy neonates (Siegel, Bauman, Schaefer, Saunders, & Ingram, 1980). However, in a study of high-risk, semi-rural families where adequate medical services were available, Olds and colleagues (1986, 1988, 1989, 1990) enhanced educational achievement, promoted employment, and reduced repeat pregnancies among young mothers with healthy infants using home visits by nonbaccalaureate prepared nurses. The visits began prenatally and extended for two years. Interventions included parent education, developing informal support systems with the parent, and linking the parent to the formal support system.

Studies related to biological risk of neonates may be difficult to extrapolate to Eastern Kentucky, because they were conducted in urban settings (Bromwich & Parmalee, 1979; Brooten et al., 1986; Hunter et al., 1978). Other investigations used a comprehensive intervention approach that was deemed effective, but information was not provided on the effects of attention versus intervention or qualifications of the home interventionist. These studies included some rural families, but their responses to an LBW child and the interventions were not addressed

separately. Generally, the studies provided support for interventions improving either parenting skills, child development, or both (Achenbach, Phares, Howell, Rauh, & Nurcombe, 1990; Nurcombe et al., 1984; Resnick, Eyler, Nelson, Eitzman, & Bucciarelli, 1987; Rauh et al., 1990).

VII. METHODOLOGY

A. Study Design

The conference was a two-day meeting of parents, policy makers, and providers of care to rural LBW children and their families. The conference was organized around themes of existing research, feasibility of using these findings with families, new directions for research, identification of other effective strategies for improving care, improving interprofessional communication, and needed health care policy changes.

A multi-phase effort was used to accomplish the Specific Aims. Phase 1 included detailed planning for the conference with an Advisory Board using participant surveys to help define conference content. Phase 2 was the conference implementation effort, while the last three phases were data analysis, evaluation of conference influence on practice, and development and implementation of a program under the auspices of a county health department to provide support to parents of LBW children. Each phase will be addressed in greater detail below.

Conference Planning Activities

Selection of the Advisory Board. An Advisory Board was appointed to assist with conference planning. The functions of the Advisory Board were to:

1. Advise on conference aims, content, learning activities, schedule, and speakers.
2. Participate in both rounds of the Delphi survey to identify child and family needs.

3. Assist in identifying conference participants.
4. Moderate sessions at the conference.
5. Contribute to the preparation of policy recommendations and the final report.

Contacts to solicit Board members were made with health departments, home health care agencies, Area Health Education Centers, Appalachian Regional Hospitals, the Commonwealth's Cabinet for Human Resources, the University's Colleges of Medicine and Nursing, the University of Kentucky Rural Health Center, and local providers known to or referred to the Principal Investigator. Parent members were identified by a neonatal nurse or by their statewide advocacy activities related to children and families with special needs. Board membership is found in Appendix A. Many of the people identified already had working relationships with each other which facilitated Advisory Board efforts.

Setting and participants. Planning sessions occurred on the University of Kentucky campus. The conference was held at the Carriage House Hotel, Paintsville, Kentucky. The hotel is located in rural Eastern Kentucky and was selected to facilitate travel for attendees. Of the 165 participants asked to attend this invitational conference, 65 attended. Participants were identified by the Advisory Board and the investigators to represent both geographically diverse areas of rural Eastern Kentucky, as well as tertiary care centers, and a broad scope of providers of health care to LBW children and their families, policy makers, and parents. Participants included physicians, nurses, home health providers, mental health providers, social workers, physical and occupational, therapists, and parents.

Participant selection criteria for health care providers and policy makers included:

1. Experience and expertise in providing care to LBW children and their families residing in Eastern Kentucky.
2. Leader in creating innovative strategies for meeting health care needs of these families.
3. Ability to improve access and health care delivery.

Parents with strong leadership activities in mobilizing care for their child and their family were selected participants. Appendix B lists participants and their affiliations.

Assessment of learner needs. Although initial conference planning was done with the Advisory Board, conference participants were identified early so that they could participate in a two-round Delphi survey technique designed to refine conference content and materials to be shared at the meeting. The first Delphi survey determined the provider-identified needs of families with LBW children. Appendix C contains a summary of those results. The second Delphi survey helped limit the list of identified needs to a smaller number which could be addressed in the conference work group sessions. A summary of those responses is found in Appendix D.

Participants were sent a description of the conference facilities, information about transportation routes to the conference, and registration information, as well as a brochure describing the conference and containing registration information. Moderators were selected from among registrants prior to the conference. The investigators made the selection with suggestions from the Advisory Board. The moderators were oriented by the investigators to their

role prior to the conference and were provided written directions about their role.

Registration packets included conference aims, abstracts of recent LBW research, conference sponsors, brochures about early intervention and support services, the Delphi survey summaries, the conference agenda, and the list of Advisory Board members.

Conference Methods

The conference methods included small group and total group sessions. Selected health policy makers and providers addressed the conference themes in the total group sessions. Drs. Virginia Rauh and Patrick Casey shared their research on models for enhancing health care to LBW children and their families, while Dr. Rice Leach addressed Kentucky health care reform related to families with children. Parents also spoke about their experiences caring for their LBW child over time.

Participants were assigned to broadly representative groups of eight members to facilitate interdisciplinary discussions. The groups were provided several opportunities for interaction prior to joining their groups. The groups were asked to: (a) evaluate existing research for potential application to the identified needs of LBW families; (b) suggest strategies to improve health care; (c) recommend policy or program changes to improve health outcomes for these children and families; and (d) identify topics for rural research on LBW children and families. Day 1 sessions focused primarily on barriers and strategies. Key points were captured on flip charts. Ideas for improving care through new approaches to health care policy and research with LBW children were suggested. Moderators met at the end of Day 1 to modify plans for Day 2, to address research application, and to propose models for improving care.

Problems Encountered

The major problem encountered was the lack of attention in the small groups to the application of existing research and to policy recommendations. Many of the policy recommendations made by the small groups required additional funding, while some ideas were not feasible. For example, suggestions for changes in eligibility requirements for disability and medical coverage were recommended.

Modifications

The investigators and moderators met at the end of Day 1 to plan strategies to redirect small group discussions on Day 2. The small groups had difficulty suggesting changes for health policy.

Because of the few recommendations for feasible policy changes from the groups, after the conference, the investigators took a different approach and met individually with state and local leaders who were interested in pursuing change. From these meetings a program, LBW Family Support Services, was developed and is being pilot tested in one county. Dissemination of the recommendations to policy makers and researchers is awaiting evaluation of the pilot program.

Post-conference Activities

An 8-month post-conference survey was mailed to all registrants to determine how the conference had altered practice. The response rate was 25%. A summary of the responses is found in Appendix E.

Phase Three: Data Analysis and Dissemination Activities

Phase 3 activities included reduction and analysis of group data which was accomplished with the help of a volunteer research assistant. Content analysis was used to analyze data. Data were verified with group moderators and by checks against key points recorded on the flip charts. A compilation of the responses were mailed to participants for comments. Their comments supported the findings.

VIII. OUTCOMES

Keynote speeches were given by Drs. Rauh and Casey, as previously described. The major message was one of communication, community involvement, and political activity. Lynn Flynn, MSW, Acting Director, Division of Maternal Child Health, Kentucky Cabinet for Human Resources, presented data on the incidence of LBW in rural Kentucky, illustrating it with graphic representations. According to conference participants, the highlight of the conference was the discussion led by parents about their concerns and the adaptations required of them from the time of their LBW child's hospital discharge until the present. They spoke of co-workers and family members who supported them, transportation needs, and financial burdens, illustrating each point with poignant stories.

Barriers. A total of 51 barriers were identified in small group sessions without any particular priority or weighting. Sixteen barriers were related to family including denial of a problem, lack of parenting skills, lack of support, transportation issues, and financial concerns. Provider issues cited ($n = 12$) were lack of family-centered care, lack of knowledge of resources, not speaking in terms parents could understand, and not taking enough time with families. Some

of the 23 system issues included financial/funding issues, lack of coordinated services, transportation issues, poor inter-provider communications, and lack of prevention emphasis in health care.

Strategies. In the brainstorming sessions, 53 strategies were developed to enhance care. Many of the proposed strategies were related to better communication, support services for parents, and transportation suggestions. Nearly all of the strategies involved expenditure of additional funds. Options suggested included designated liaisons between service programs, widely disseminated and frequently updated resource manuals, more referrals to meet needs, efforts to develop coping skills in families and providers, preventive interventions, parent education programs, improved curricula for health providers, respite care for parents, satellite clinics, and specialized day care.

These issues were collapsed into six general categories at the end of Day 1 and became the focus for group work in Day 2. The issues were: (a) coordination of services at the family level; (b) coordination of services at the system level; (c) financial resources; (d) parent and public health promotion/illness prevention education; (e) transportation; and (f) provider issues (practice, accessibility, education, and the mix of rural providers).

The second day the groups, under the guidance of group moderators, made a number of useful suggestions for overcoming barriers identified the previous day. For example, participants suggested that existing systems be evaluated for gaps and that new coordination systems be implemented and evaluated based on a review of the research literature on existing systems. The participants strongly emphasized the need for consumers to be involved, in addition to

developing community-based models.

Many suggestions related to provider issues, although several of the ideas proposed were already being implemented to some degree. They suggested training and re-training for rural providers. This already occurs through Area Health Education Centers, and University continuing education programs. For people lacking insurance, they suggested medical cards if the children were ineligible.

The group recommended greater use of computer technology to share databases. School-based family health and resource centers were recognized as valuable, and the need to expand them into more areas was acknowledged. There was a strong plea to have one coordinator of services for each family, although no strategies were suggested to accomplish this goal.

IX. SIGNIFICANCE

The amount of agreement on barriers to care and strategies for overcoming the barriers was encouraging. With so much similarity between different rural areas, changes in service delivery to address these issues should generalize across counties and regions.

Ms. Dorothy Redfern, a nursing consultant from the Maternal-Child Health Bureau Atlanta office, summarized conference accomplishments for the participants. She echoed the themes developed in the groups, emphasizing prevention, and suggesting that services be individualized rather than focusing on program guidelines. Simplicity of interventions was another point of emphasis, as well as combining resources to deliver services, thereby eliminating duplication, and enhancing services. Joint funding of transportation with other community agencies was suggested. Local, community-based planning was emphasized, as well

as consumers' input into policy changes. A summary of group points related to barriers, strategies, and recommendations is located in Appendix F.

Post-conference Activities

The results of the conference were discussed by the PI and Co-PI with several administrators in the state Office of Maternal Child Health. One county was selected as the implementation site for a LBW Family Support Services program. Selection criteria were: (a) a county with a well-organized, innovative health department; (b) good working relationships with other agencies; and (c) an identified, unmet need for services to families with LBW children.

A proposal, developed by the PI and Co-PI, was discussed with the county health department, and sent to the state for funding approval. (See Appendix G for a copy of the proposal.) Evaluation of program effectiveness will be done by the investigators. Program implementation will begin with recruitment and training of personnel. The Principal Investigators were assisted in the training efforts by RNs and MDs from a Level II neonatal nursery at the Pikeville Methodist Hospital. Recruitment and training of personnel for the one-year pilot program began with partial support from private funds. If successful, efforts will be initiated to expand the program to other areas of the state.

X. PUBLICATIONS/PRESENTATIONS

A. Publications

1. Sachs, B., & Hall, L.A. (1996). Rural families and low birth weight babies.

Rural Health Initiative, a University of Kentucky Publication, 4(1), p. 2.

2. Sachs, B., & Hall, L.A. (in review). A community partnership model to enhance care for rural families with low birth weight children. Submitted to Journal of Rural Health. (copy in Appendix H).

B. Presentation

Sachs, B., & Hall, L.A. (1995). "Rural Low Birth Weight Children and Their Families: Needs and Services." Louisville, Ky.: Kentucky Infant-Toddler Conference, July 28-29, 1995.

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Appendix A
Advisory Board Members

ADVISORY BOARD

- *Beth Ball, MSW, King's Daughters Hospital, Ashland, KY
- *Ruth Beeman, CNM, MPH, March of Dimes, East Kentucky Chapter, Lexington
- *Judy Elam, MSN, RN, Appalachian Regional Healthcare Home Health Agency, West Liberty
- *Mary Fox, MD, Former Director, Pike County Health Department, Pikeville
- *Karen Hinkle, Executive Director, Kentucky Home Health Agency, Lexington
- *Karen Middendorf, MEd, University of Kentucky, Director, Interdisciplinary Human
Development Institute
- *Linda Moon, BS, RN, Nursing Consultant, Cabinet for Human Resources, Frankfort
- Mary Murry, MSN, CNM, RN, Maternity Center, St. Claire Medical Center, Morehead
- Thomas Pauly, MD, Chief, Division of Neonatology, Department of Pediatrics, University of
Kentucky
- Debbie Raftery, MSW, Division of Neonatology, University of Kentucky
- *Curtis Rowe, MPH, Appalachian Regional Healthcare, Lexington
- *Ruth Shephard, MD, Methodist Hospital of Pikeville, Neonatology Division
- Lori Shook, MD, Division of Neonatology, University of Kentucky
- *Amy Snell, RN, Division of Neonatology, University of Kentucky

*Active Board members

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Appendix B

List of Attendees and Their Agency Affiliations

Mary Abney
Powell County Health Dept.
PO Box 460
Stanton, KY 40380

Janet Barry
Pathways, Inc.
2200 Lexington Avenue
Ashland, KY 41101

Pat Berdine
University of Kentucky
224 Mineral Industries Bldg.
Lexington, KY 40517

Nancy Combs
KY River District Health Dept.
Box 189
Vicco, KY 41773

Vicky Dyer
Magoffin County Health Dept.
Box 610
Salyersville, KY 41465

Teresa Free
University of Kentucky
315 College of Nursing
760 Rose Street
Lexington, KY 40536

Paul Hopkins
Pike County Health Dept.
100 River Drive
Pikeville, KY 41501

Mary Anne Janowski
Comprehensive Care-Corbin
PO Box 568
Corbin, KY 40702

Jeannie Bailey
Big Sandy Health Care
Salyersville, KY 41465

Mary Beth Baumgardner
Pathways, Inc.
PO Box 790
Ashland, KY 41101

Diane Blackburn
Johnson County Health Dept.
630 Trimble Blvd.
Paintsville, KY 41240

Kelli Fleeman
Kings Daughters Medical Center
3142 Winchester Avenue
Ashland, KY 41102

Patricia Fugate
KY River District Health Dept.
Box 189
Vicco, KY 41773

Kathy Hembree
Magoffin County Health Dept.
PO Box 610
Salyersville, KY 41465

Janet Hovekamp
UK Medical Center
NICU Graduate Clinic
Lexington, KY 40536

Adena Justice
Pike County Health Dept.
100 River Drive
Pikeville, KY 41501

Karen Baldwin
Mountain Comp Care
1032 Broadway
Paintsville, KY 41240

Ruth Beeman
March of Dimes
3475 Lyon Drive #78
Lexington, KY 40513

Martha Blair
Cumberland Valley District Health Dept.
402 East Clover Street
Harlan, KY 40831

Dennis Chaney
Morgan County ARH
PO Box 579
West Liberty, KY 41472

Lynne Flynn
Cabinet for Human Resources
Division of Maternal & Child Health
Frankfort, KY 40621

Agripina Grino
609 Trimble Blvd.
Paintsville, KY 41240

Glenna Nixon
Hazard Regional Medical Center
100 Medical Center Drive
Hazard, KY 41701

Tamara Ratliff
Mountain Comp Care
PO Box 1340
18 South First Street
Prestonsburg, KY 41653

Ginger Perry
Morgan County ARH
Home Care Hospice
West Liberty, KY 41472

William Pratt, MD
202 West 7th Street
Medical Arts Bldg.
London, KY 40741

Montiel Rosenthal, MD
Saint Clair Medical Center
PO Box 748
Sandy Hook, KY 41171

Amy Snell
UK Medical Center
Division of Neonatology
800 Rose Street MS 463
Lexington, KY 40536

Kathy Walter
Morgan County ARH
PO Box 579
West Liberty, KY 41472

Julya Westfall
Eastern Kentucky University
364 Rice School Road
McKee, KY 40447

Mary Simmons
Dorman Preschool
1204 Main Street
Shelbyville, KY 40065

Kathy Watkins
ADANTA
72 Southland Drive
Somerset, KY 42501

Denise Weiss-Salinas
Eastern Kentucky University
256 Rice School Road
McKee, KY 40447

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Appendix C
Delphi Survey One

UNIVERSITY OF KENTUCKY
COLLEGE OF NURSING

***Rural Low Birth Weight Children and Their Families:
Visions for the Future***

Summary of Delphi Survey 1

1. What are the common unmet health needs of rural low birth weight (LBW) children and their families in Kentucky?

	<u># of responses</u>
• Coordination of services	1
• Support services for families (caretakers)	4
- Inadequate home health services	1
• Unavailable parenting classes	1
• Prevention education	6
• Better "training" for caretakers	1
• Acute illness care if family lacks 3rd party payor	2
- Some pediatricians don't accept Medicaid	1
• Transportation for specialized services	4
• Lack of therapeutic services (PT, OT, ST) locally	6
• Respite care	1
• Lack of ophthalmology care	1
• Family financial needs	1
- Other siblings	1
• Lack of parental education	1
• Lack of motivation (will) to change [or depression]	1
• Home assessment needed prior to hospital discharge	1
• Early intervention, infant stimulation programs	5
• Referral for treatment of behavior disorders (see above)	1
• Nutrition, weight gain, feeding techniques	2
• Lack of knowledge of available services	1
• Inadequate monitoring	1
• Easy communication with responsible, but distant, MD	1
• Day care for other siblings	1

2. What community resources are currently available to help these families?

	<u># of responses</u>
• Many available, fragmented, accessibility are problems	2
• Health departments	11
• Parenting classes	2
• FRC	2
• Early intervention	3
• Community mental health services	5
• Private physicians	5
• Social insurance programs	4
- WIC	6
- Immunizations	1
- KEIS (Kentucky Early Intervention Services)	6
• Commission for Children with Special Health Care Needs	4
• UK regional clinics	2
• Home health services - where available	7
• AFDC for transportation, food stamps	5
• FMHA for housing	1
• Lions Club	1
• Head Start	2
• Churches	1
• Nutrition services	1
• Well child exams	3
• Hospitals/clinics	6
• EPSDT	1
• CHIPS (??)	1
• R-Tec (resp services)	1
• Social services	1
• CDC (Richmond) ??	1
• OT, PT, etc.	1

3. Which ones are used?

• All, but infrequently	8
• Health Department	4
• WIC	3
• Home health	2
• Depends on age of child or family needs	1
• Social services	1
• Prenatal service centers	1
• Free	1
• Accessible	1
• In-home services	2
• Well-child care	2
• Infant stimulation	1

4. Which ones are not used?

	<u># of responses</u>
• No response (some thought it an inane question)	6
• Depends on family knowledge, resources, coping	3
• Speech, PT, OT	1
• Home health services	1
• Support groups	1
• Not applicable	1
• Early intervention	1
• Those with fees	1
• Regional Peds	1
• Rtec	1
• CHIPS	1
• Not sure	1

5. What do you perceive to be the barriers to health care?

• Transportation	9
• Lack of service coordination/case management	4
• Poor tertiary/community-based service linkages	1
• Lack of appropriate referrals	2
• Parental lack of priority for well-child care, prevention	1
• Lack of info (on whose part?) [Parents/MDs]	7
• Lack of understanding by parents	5
• Denial by parents	1
• Payment problems/cost	3
• Fear	1
• Lack of agency skill	1
• Lack of time and funds to work with other agencies	1
• Long waits for services	1
• Parental overload	1
• SES	2
• Denial of problems (grow out of) by professionals	1
• Child care for siblings	1
• Decentralized info	1
• No response	1

6. What services are needed but not available?

	<u># of responses</u>
• Educational systems for parents	1
• Professional service coordinator system	4
• Hands on assistance to caretakers	1
• Hearing/vision services	1
• Pediatricians in every county	1
• PT/OT, etc. (wont' accept pediatric patients)	2
• Developmental programs at local level	2
- Developmental preschools	1
• More local services	1
• Home-based intervention team	1
• Education on LBW	3
• LBW day care	1
• Support groups	1
• Means to access the system	1
• Services for middle income families	1
• Transportation	2
• <u>Adequate</u> home health for high risk pregnancy	1
- Accessible prenatal care	1
• Rehabilitation services	2

7. What aspects of care need to be improved to better serve these families?

• Greater awareness by professionals of special needs of this population	3
• Collaborative nature of services needs to be improved	3
• Service coordination	2
• Quality local care	2
• Greater prevention emphasis (education)	3
• All care aspects	1
• Decreased waits	1
• Improved transportation services	2
• Public information campaigns	1
• Better understanding of family systems	2
• Improved early case findings and intervention	2
• Improved family assessment	1
• Improved accessibility	1
• Prenatal care (it's available in every county)	1
• Improved communication between tertiary MD and parent after discharge	1
• Improved rehabilitation services	1
• No response	1

8. How useful would you find the approach outlined for stimulating your thinking about new or enhanced approaches to care for LBW children and families?

Very useful 6
 Useful 8
 Not very useful 2
 Frustrating 1
 Not at all useful 0
 No response 1

9. What alternative approaches could you suggest?

	<u># of responses</u>
• No response	10
• Coordination of services via intake triage and referral	2
• Focus groups to look at different issues	1
• Hire a parent to role model effective parenting	1
• Include foster parents	1
• Include MDs - plenty of them	1
• Develop video specific to care of LBW and distribute to various providers	1
• Mentoring system for new LBW parent with experienced one	1
• Toll free hot line to tertiary center for parents and providers	1
• Small group sessions	1

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Appendix D
Delphi Survey Two

**RURAL LOW BIRTHWEIGHT CHILDREN AND THEIR FAMILIES:
VISIONS FOR THE FUTURE**

**SUMMARY OF DELPHI SURVEY #2
(N = 53)**

Below are the results of the second Delphi Survey in which 53 individuals participated. Items were weighted and rank ordered according to the points received on the second survey. The top 10 priorities that resulted are listed under each category (i.e., unmet health needs, care improvements, needed services, and barriers to care).

**Top 10 Common Unmet Health Needs of Rural LBW
Children and Their Families in Kentucky**

1. Prevention education (50 points)
2. Family financial needs (43 points)
3. Early intervention, infant stimulation programs (41 points)
4. Parental lack of knowledge about available services (36 points)
5. Lack of therapeutic services locally (e.g., PT, OT, speech therapy) (35 points)
6. Lack of parental education (32 points)
7. Lack of motivation on the part of the family to change (28 points)
8. Coordination of services (27 points)
9. Transportation to specialized services (26 points)
10. Acute illness care for families who lack third party payer (25 points)

**Top 10 Aspects of Care that Need to be Improved
to Better Serve These Families**

1. Improved access to care (42 points)
2. Greater awareness by professionals of the special needs of this population (37 points)

3. Greater prevention (education) emphasis (36 points)
4. Professional service coordination system (30 points)
5. Improved early case finding and intervention (27 points)
6. Prenatal care (26 points)
Improved communication between tertiary physicians and parents after discharge (26 points)
7. Improved transportation services (22 points)
Service coordination (22 points)
8. Quality local care (21 points)
9. Better family assessment (19 points)
10. Decreased waits for care (17 points)
Educational systems for parents (17 points)
Hands-on assistance to caretakers (10 points)

Top 10 Services Needed But Not Available

1. Transportation (56 points)
2. Developmental programs locally (developmental preschool) (45 points)
3. Pediatrician in every county (36 points)
Adequate home health services for high-risk pregnancy (36 points)
4. Services for middle income families (32 points)
More local services (32 points)
5. Home-based intervention team (29 points)
6. Educational systems for parents (28 points)
7. Professional service coordinator system (24 points)
Accessible prenatal care (24 points)
8. LBW day care (23 points)

9. Physical therapy and occupational therapy (21 points)
10. Hands-on assistance to caretakers (20 points)

Top 10 Barriers to Health Care

1. Payment issues/cost of care (40 points)
2. Lack of service coordination/case management (32 points)
3. Transportation (28 points)
4. Denial of problems by parents (24 points)
5. Long waits for services (23 points)
Lack of information about ? (23 points)
6. Poor linkages between tertiary and community-based services (21 points)
7. Lack of family priority for preventive services (18 points)
8. Lack of appropriate referrals (16 points)
9. Lack of agency skill (15 points)
10. Lack of parental understanding (14 points)
Parental overload (14 points)

Appendix E

Summary of 8-Month Post-Conference Survey

UNIVERSITY OF KENTUCKY
COLLEGE OF NURSING

Rural Low Birthweight Children and Their Families: A Consensus Survey

Summary Sheet

Directions: Listed below are the barriers to more effective health care for rural low birthweight children and their families. You identified these barriers at the LBW conference in Paintsville, Spring 1995. The barriers are followed by your recommended strategies. Please rate the importance of each barrier and strategy for improving health care for these families.

N = 15

Response rate = 25%

1 = Not at all important

2 = Somewhat important

3 = Important

4 = Very important

Category/Item

Mean # of respondents

I. FISCAL ISSUES

A. Family barriers

1. Middle income families have no support; caught in issues of insurance coverage	3.46	15
2. Financial burden of care	3.80	15
3. Dehumanizing reimbursement process	2.86	15

B. Strategies to address family barriers

1. Medical cards for those unable to get SSI or private pay	3.25	12
2. Less complex eligibility requirements	3.58	14
3. Standard requirements	2.77	13
4. Statewide service for equitable coverage	2.93	14

C. Cost controls

1. Paying for services rendered (do not pay for PT when PTA renders)	3.35	14
2. Contract for pharmacy providers to reduce costs	3.28	14
3. Address fraud	3.28	13

D. Payment mechanisms

1. Electronic food stamps	3.86	15
2. Reverse payment mechanisms	2.64	14
3. Service vouchers instead of cash	3.00	15

E. Sources of funding

1. Private	2.85	13
2. Corporate	2.92	13
3. Taxation: Increase cigarette taxes	3.25	12

F. Payment mechanisms

1. Use existing resources to tap into new ones	2.92	13
2. Decentralize control of funding to local communities	2.79	14
3. Develop services for prevention	3.33	15

	<u>Mean</u>	<u># of respondents</u>
G. Funding/services required but not available		
1. Incentives for prenatal care	3.40	15
2. Incentives to recruit providers to rural area	3.21	14
3. Funding to train/retrain rural providers; training grants for rural providers (AHEC, etc.)	3.07	14
4. Funding for resource center to give out info and train (who, what?)	2.92	13
5. Funding for innovative programs; funding for at least 4 pilot programs	3.15	13
6. Expand WIC (for what)	3.07	14
7. Expand providers accepting Medicaid	3.23	13
II. COMMUNICATION, COORDINATION, AND COLLABORATION		
A. Barriers		
1. Lack of cooperation between providers	3.31	13
2. Fragmented care delivery; lack of coordinated services	3.53	15
B. Communication		
1. Community resource manuals	2.79	13
2. Discharge meetings with all providers present (lack of formal referrals)	2.71	13
3. F/U care for discharges; refer families for F/U; community-based F/U	3.62	13
4. Improve referral system	3.43	14
5. Lack of knowledge of available resources; knowledge of community resources	3.27	15
6. Interagency community meetings	3.50	6
7. Develop regional computer data bases (issues of privacy)	2.93	13
8. Improved communication between providers	3.47	15
9. Dedicated phone line for Ask A Nurse; built in liaisons between service programs	3.06	15
C. Coordination		
1. Coordination of all interagency coordinating bodies Interdisciplinary, interagency group	2.93	15
2. One person coordinating services Primary service coordinator for ongoing care	3.06	15
3. Centralized coordination; statewide system for support, care, communication	2.79	14
4. Review literature for coordination models	2.67	15
5. Review existing service coordination programs in Kentucky	2.80	15
6. Regionalized services, satellite clinics, convenient	2.92	12
7. Analyze existing systems for gaps, duplication of services, payments	3.40	15
D. Collaboration		
1. With churches, hospitals, schools (purpose?) to use resources	3.27	15
2. Interagency for families with many services	3.20	15
3. Single point of entry	3.20	15
4. Improve client advocacy; service to families	2.73	15

III. FAMILY BARRIERS**A. Attitudinal/psychological**

1. Lack of motivation to seek appropriate care	3.0	15
2. Denial of problem	3.0	15
3. Unhealthy lifestyles, poor nutrition	3.53	15
4. Need for child to remain ill	2.53	15
5. Low self esteem (teen pregnancies)	3.33	15
6. Fear of leaving local area	2.67	15

B. Educational

1. Lack of general education	3.67	15
2. Lack of parenting skills; inability to deal with behavior problems	3.67	15
3. Unaware of importance of prenatal care	3.46	15
4. Need for positive role models		
5. Lack of support for family	3.67	15

C. Strategies

1. Support system for parents of child with behavioral problems	3.40	15
2. Support group - buddy system to appointments	3.21	14
3. Assist families with coping skills, financial need, behavioral needs	3.53	15
4. Families mentoring families	3.27	15
5. Family-centered support	3.27	15

IV. PROVIDER PREPARATION**A. Knowledge barriers**

1. Providers poorly trained to meet children's specific needs	3.20	5
2. Person with strong pediatric background	3.54	13
3. Lack of knowledge of equipment, technology	3.86	14
4. Lack of subspecialty care	2.93	14
5. Lack of child development education	3.21	14
6. Lack of knowledge of client needs	2.93	15
7. Lack of developmental interventions	2.93	14
8. Faulty assumptions about what other providers know	2.85	13
9. Provider shortage (Community Health nurses and therapists)	3.27	15

B. Strategies

1. More community focus for health curricula	3.33	15
2. Trained pediatric staff	3.27	15
3. Specially trained with technology skills	2.87	15
4. Increase interdisciplinary training programs	3.20	15
5. Enforce continuing education requirements; locally based CE	3.13	15
6. Recommend specific LBW CE courses for all disciplines	3.33	15
7. Increase scope of practice for providers	3.21	14
8. Restrictive practices for NP and CNM	2.93	15

V. PROVIDERS PRACTICE**A. Barriers**

1. Hours of service delivery	3.00	13
2. Lengthy waits for services	3.06	15
3. Not explaining at parent level of understanding	3.36	14
4. Insensitive to cultural diversity	3.08	14
5. Not outlining expectations for child health and development	3.20	15
6. Turf issues (control)	2.79	14

B. Strategies

1. Schedule appointments to reduce waiting time	3.08	13
2. Family-friendly interventions	3.36	14
3. Parent education by provider	3.46	13

VI. ORGANIZATION OF SERVICES**A. Strategies**

1. Experienced NICU nurses in every county	3.07	15
2. Getting needed mix of providers to local area	3.33	15
3. More flexible, comprehensive home-based services	3.20	15
4. Explore models in other states-models to meet Kentucky needs	3.00	15
5. More parent/teacher involvement	3.07	15
6. Specialized day care	3.20	15
7. Breast feeding support	2.67	6
8. Respite services	3.71	7
9. Youth Center - use for prenatal care appointments; use KERA F&Y services for prevention, case finding, some care	3.07	13
10. All schools have Family Resource Center	3.17	12
11. Poor image of health department	2.75	12
12. Reasonable case load	3.25	12
13. Develop guidelines for services needed	2.92	12
14. Individualized non-emergency services	2.92	12
15. Provision of therapy to children in school setting	2.86	14

VII. MARKETING/PUBLIC RELATIONS**A. Strategies**

1. Public information ads for services available Marketing of services Market services: print and electronic media	3.23	13
2. Educate public to comparison shop for service	2.77	13
3. Educate parents, providers, and the community	3.43	14

VIII. HEALTH PROMOTION/DISEASE PREVENTION**A. Barrier**

1. Failure to emphasize prevention	3.60	15
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B. Strategies

1. Early case finding, emphasis on prevention; first steps	3.47	15
2. Prevention education programs	3.53	15
3. Prevention/management of behavior problems	3.60	15
4. Enhance positive lifestyles; allow teaching all aspects of healthy lifestyles, prevention	3.53	15
5. Develop prenatal risk assessment monitoring system	3.40	15
6. Increase awareness of fragile child needs	3.50	14

IX. RESEARCH**A. Strategies**

1. Studies needed to review successful service coordinating systems	3.29	14
2. Require community survey of health needs (who requires, of whom?)	3.07	14
3. Evaluate pilots; look at child/family outcomes	2.93	14
4. Consumer evaluation of system - survey, focus groups	3.00	15
5. Develop outcome studies based on data	3.14	14

X. POLICY**A. Barrier**

SSI policies not prevention oriented	3.64	14
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B. Strategies

1. Gain state commitment for support families Get buy-in of critical stakeholders	3.43	14
2. Assure consumer involvement in policy development	3.93	14
3. Parent group to talk with legislators about their service, funding	3.07	14
4. Law requiring one to be 16 to be married	2.93	14

XI. TRANSPORTATION**A. Strategies**

1. CATS	3.33	12
2. Neonatal transport to Ashland and Lexington	3.57	14
3. Caps on transportation fees (fiscal)	3.27	15
4. Public transportation (? in rural areas)	3.50	14
5. Bus and taxi vouchers; Medicaid taxi	3.14	14
6. Air transportation	3.29	7
7. 1-800 TRANS number (communication)	3.17	12
8. Volunteers to drive vehicles	3.10	10

Appendix F

Summary of Barriers to Care

Strategies to Overcome Barriers

Recommendations

LBW Conference- Paintsville

Identified Barriers-

Family:

- denial of problems
- fear of leaving local area for help
- financial burden
- lack of effective parenting skills
- lack of motivation
- lack of support for families
- lack positive role models for children
- need for child to be sick
- poor attitudes
- poor education
- teen pregnancies- low self-esteem, malnourished
- transportation
- unable to stay with hospitalized child
- unaware of importance of prenatal care
- unhealthy lifestyles
- unprepared for dealing with behavioral problems

Provider:

- care not family centered
- denial of problems
- faulty assumptions about what other providers know
- lack knowledge of available resources
- lack knowledge of equipment, technology needed
- lack understanding of client needs
- not speaking at level of pt/family understanding
- not telling parents what to expect
- poor education/training for specific needs
- poor sensitivity to cultural diversity
- private practices have many patients, little time
- turf issues

System:

decreased number of nurses prepared for community work
different eligibility requirements for different programs
fragmented care
funding
lack of central services
lack of child developmental education
lack of developmental interventions for at-high-risk kids
lack of service coordination
long waits for services
no subspecialty care in some areas
people from different backgrounds not working together
political climate- funding cuts
poor communication between providers- no formal referral
poor prevention strategies
poor public perceptions of health departments
poorly trained pediatric personnel
prevention not a priority
pull-out of private insurance
restrictive practice acts for independent NP's and CMW's
services not for middle income families
SSI policy- fosters developmental delay and disability
therapist shortage in rural areas
transportation

Issues identified on Day One for discussion on Day Two:

Coordination of Services at Family Level
Coordination of Services at System Level
Financial Resource
Prevention- parent and public education
Provider Issues (practice, education, nix, availability)
Transportation

LBW Conference- Paintsville

Strategies:

1-800 number for transportation
address turf issues to coordinate care
"Ask a Nurse"- at tertiary centers for local providers to call
become aware of needs for more fragile children
breast feeding support
built-in liaisons between service programs
caps on transportation fees
community resource manuals for providers
control costs
convenient services
coordinating team to identify needs and provide referrals
creative education programs
database available to all providers with updated info
develop coping skills for families and providers
develop creative methods to use services available
discharge meetings/ intake day with all services present
early case finding and prevention intervention
educate parents, providers, and community
education focused on improving lifestyles
electronic food stamps
encourage families to speak with legislators
enlist aid of benevolent community groups
expand WIC
families mentoring each other
family friendly interventions
follow-up care to discharges
grants for providers working in rural areas
health curriculums to focus on community care
improve client advocacy
incentives for prenatal care
increase interdisciplinary training programs
increase tax on cigarettes
interagency meetings in the community
less complicated eligibility requirements for services
local continuing education
marketing services
more flexible and comprehensive home based services
NICU grad nurse in every community
primary service coordinator for ongoing care

regionalize services
respite care
restrict minors smoking cigarettes
satellite clinics
service vouchers instead of cash entitlements
shorten long waits for care
single point of entry into system
specialized day care
statewide support coordinating program
statewide transportation service with equitable coverage
stop duplication of services
stress need for services to families
support groups
system wide coordination of care and communication
youth service centers at high schools for teen parentse

Day Two

Financial Issues

- address formula fraud- reimburse stores per can bought
- avoid dehumanizing the reimbursement process
- child care vouchers instead of cash
- decentralize control of funding sources to local communities
- educate public to comparison shop for services
- families caught in issues of insurance coverage
- funding for resource center to give out info and train
- funding to train/retrain rural providers
- lower costs by contracting with pharmacy by providers
- medical cards for kids unable to get SSI or private pay
- paying for services rendered- paying for PT, but done by PTA
- providers accepting Medicaid

Provider Issues

Distribution

- getting mix of providers needed to needed area
- improve education
- make incentives to help recruit providers
- marketing
- reverse payment mechanisms

Availability

- develop guidelines for what is needed
- hours of operation
- increase knowledge of providers
- increase scope of practice for providers
- require community survey
- satellite clinics

Maintaining State of the Art

- develop regional data bases using computer technology
- enforce continuing education requirements
- recommend specific LBW CE courses for all disciplines

Policy/ Payment

- develop innovative ways to distribute existing resources
- develop policy to assure payment for preventive services
- prevent duplication of services and payment

Research

- develop prenatal risk assessment monitoring system
(longitudinal study to age specifics)
- develop outcome studies based on data
- use existing resources to tap into new resources

Transportation

Funding

- civic groups/ church groups
- corporate
- Medicaid
- private funding

Emergency Transportation

- air transportation
- inappropriate use of
- individualize non-emergency services
- NICU transport to Ashland and Lexington
- trained pediatric staff

Non-Emergency Transportation

- bus/ tax vouchers
- CATS
- Medicaid taxi
- public transportation
- school systems- child to receive therapy in school
- social services

Strategies

- collaborate with churches, hospitals, schools
- early intervention/ First Steps
- home health non-medical transportation
- support group- buddy system to appointments
- UK f/u clinic to travel around state
- volunteers to drive vehicles
- youth center- use for prenatal care appointments

Supporting Individual Families

Practice --family with one person coordinating services
contact beginning with admission to level two or three
coordination is long-term (at least till enters school)
family centered support
health/ medical focus
knowledge of community resources
may provide services as appropriate
person with strong pediatric background
reasonable case load
refers family for F/U
specially trained with technology skills

Policy--gain state commitment for supporting families
develop by interdisciplinary interagency group
don't duplicate services
explore models in other states
funding for at least four pilot programs- urban and rural
get buy-in of critical stakeholders
model to meet KY needs

Research

evaluate pilots- look at child-family outcomes
research existing KY service coordination programs
review literature for models for coordination of families

Prevention: Parent/ Public Education

Issues to be addressed

begin early in life
more parent/teacher involvement
need for positive role models
support system for parents with hard to control child

Policy

all schools with family resource center
allow teaching all aspects of healthy lifestyles/prevention
expose children to career choices
funding for innovative programs/ or classes for kids
interagency collaboration for families with many services
law requiring one to be 16 to be married
public information/ads for services available
smaller student:teacher ratios
teach goal setting- starting in kindergarten

Research

learn how kids choose role models
management/ prevention of behavior problems

Coordination of Services at Systems Level

analyze existing systems for gaps
assure consumer involvement in policy development
centralized service coordination- build on KEIS, health depts.
community based system for f/u of all high risk kids
computer data bases to share patient info among agencies
consumer evaluation of system- survey focus groups
coordination of all interagency coordinating bodies
improved communication between providers
interdisciplinary training/ collaboration
research to review successful service coordination systems

What to do now.....

Review literature for the following-

- common problems among LBW children related to age
- computerized databases
- innovative public education programs
- service coordination systems
- traveling clinic vans

Examine present policies and programs-

- education done at d/c @ what to expect
- funding of programs- identify existing problems
- how family centered care is approached by providers
- types of education programs available

Develop-

- 1-800-# to give out service information
- Ask-a-Nurse at hospital NICU for providers to call
- education materials to give out
- more health education programs
- parenting skills classes
- support groups- families supporting each other

Important areas identified at the conference...

- Education- of parents and providers about what to expect of LBW children as they get older and services they'll need.
- Database/ Service Coordination- a central place to get needed info about a patient and available services and one person to follow child from birth till school-age.
- Support- for families and providers to form a more unified system working together.

Some ideas...

- A class in the CON for education students to focus on health issues that can be addressed in the school system.
- Have MSN students do some of the reviews of literature for their research projects.
- Look at possibility of an advanced computer class taking on the the development of a database as a class project.

Appendix G excluded

